

REMARKS OF
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CHAIRMAN,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
BEFORE
THE NATIONAL COUNCIL ON PATIENT INFORMATION AND EDUCATION
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I AM PLEASED TO BE ABLE TO JOIN YOU THIS MORNING. THESE DAYS IT IS NOT OFTEN THAT I AM INVITED TO A GROUP TO DISCUSS ETHICS AND MORAL RESPONSIBILITIES IN HEALTH CARE. A FEW YEARS AGO, I SPOKE FREQUENTLY ABOUT THE RIGHT TO HEALTH CARE OR THE OBLIGATIONS OF THE NATION TO PROVIDE FOR ITS SICK. BUT NOW I AM USUALLY REQUESTED TO DESCRIBE STATISTICS ON DEDUCTIBLES AND COPAYMENTS AND FORMULAS.

PATIENT INFORMATION AND EDUCATION CAN BE SUPPORTED BY BOTH TYPES OF ARGUMENTS--STATISTICAL AND ETHICAL.

IN NUMERICAL TERMS IT IS EASY TO DEMONSTRATE THAT EDUCATION AND PREVENTIVE MEDICINE YIELD RETURNS AS HIGH AS A HUNDRED TO ONE.

* THE COST OF INFORMING PARENTS ABOUT THE DANGERS OF LEAD-BASED PAINT ARE MINISCULE IN COMPARISON TO THE COSTS OF CARING FOR A RETARDED CHILD.

* THE EFFORT NEEDED TO DESCRIBE THE SODIUM CONTENT OF FOODS AT HOME MAY PREVENT THE NEED TO DEAL WITH HYPERTENSION AND HEART DISEASE IN A HOSPITAL.

EVEN IN CLASSIC ECONOMIC THEORY, INFORMATION IS THE SELF-CORRECTING FEATURE OF THE MARKETPLACE. IT ENCOURAGES ALL PARTICIPANTS TO ALLOCATE THEIR RESOURCES MOST EFFICIENTLY. IN THEORY, IT THUS IMPROVES THE TOTAL RESOURCES FOR SOCIETY. THE REGULATION OF THE FAIR DISSEMINATION OF THIS INFORMATION IS ROUTINELY ACCEPTED AS PART OF THE STOCK AND BOND MARKETS. IT IS ADVOCATED BY THE MOST RESPECTABLE OF CONSERVATIVES AND NOW FORMS THE FRAMEWORK OF FINANCIAL MARKETS.

BUT, BEYOND THESE ECONOMIC ARGUMENTS, THERE IS A FUNDAMENTAL ETHICAL ARGUMENT THAT ALL PEOPLE--WHETHER INVESTMENT BANKERS OR PREGNANT TEENAGERS--SHOULD HAVE THE INFORMATION TO PROTECT THEMSELVES FROM HARM AND TO MAKE DECISIONS INDIVIDUALLY. SUCH RIGHTS OF SELF-PROTECTION AND SELF-DETERMINATION ARE MOST IMPORTANT AND SOMETIMES MOST COMPLICATED IN HEALTH.

IN THE SHORT RUN, THE WORK OF EDUCATION AND INFORMATION MAY SOMETIMES APPEAR TO BE TOO EXPENSIVE OR CUMBERSOME FOR BUSINESS OR PROVIDERS.

IN THE LONG RUN, HOWEVER, IT IS ECONOMICALLY AND ETHICALLY BEST FOR ALL CONCERNED. THOSE WHO DISCOURAGE THE EXCHANGE OF INFORMATION--LIKE THOSE WHO WOULD USE INSIDER INFORMATION IN THE STOCK

EXCHANGE--DO SO ONLY OUT OF SELF-INTEREST THAT IS NEITHER MORALLY ACCEPTABLE NOR ECONOMICALLY EFFICIENT.

IT IS CLEAR TO ME THAT THE QUESTION IN HEALTH EDUCATION IS NOT WHETHER TO DO IT, BUT HOW IT CAN BEST BE DONE. IN A SOCIETY THAT IS SOMETIMES OVERPOWERED BY "FUTURE SHOCK" TECHNOLOGY, WE MUST ALSO DECIDE HOW MUCH GOVERNMENT INTERVENTION IS HELPFUL:

* GOVERNMENT CAN MAKE THE ENTIRE DECISION, AS ALL FIFTY STATES DO WHEN THEY REQUIRE THAT ALL CHILDREN BE IMMUNIZED AGAINST POLIO.

* GOVERNMENT CAN REGULATE THE PUBLIC'S DECISION, AS IT DOES WHEN IT MAKES SOME DRUGS AVAILABLE BY PRESCRIPTION.

* GOVERNMENT CAN REQUIRE THAT THE PUBLIC BE GIVEN DECISION-MAKING INFORMATION, AS IT DOES BY REQUIRING THAT CIGARETTES BE LABELED WITH CANCER WARNINGS.

* OR GOVERNMENT CAN HOPE THAT PRIVATE ENTERPRISE WILL SOMEHOW INFORM THE PUBLIC OF RISKS, AS THE REAGAN ADMINISTRATION HAS NOW DONE BY MAKING PATIENT PACKAGE INSERTS VOLUNTARY.

I AM SURE THAT IT WILL STARTLE NONE OF YOU TO KNOW THAT I BELIEVE THAT THE FEDERAL GOVERNMENT HAS A GREATER RESPONSIBILITY THAN MERELY TO HOPE FOR THE BEST.

TO THE EXTENT THAT DANGERS ARE ISOLATED AND WELL KNOWN, IT IS

PERHAPS APPROPRIATE TO LET THE MARKET WORK ITS WILL.

BUT WHEN CHILDREN OR UNINFORMED CONSUMERS ARE INVOLVED OR WHEN THE PUBLIC AT LARGE IS AT ECONOMIC RISK OR HAS ITS HEALTH JEOPARDIZED, SUCH A "HANDS-OFF" POLICY IS A MARKET FAILURE THAT COSTS THE COUNTRY BILLIONS IN SICKNESS AND CARE.

AT PRESENT THE FEDERAL GOVERNMENT DOES VERY LITTLE TO REGULATE CONSUMER INFORMATION OR CHOICE. SINCE ONE QUARTER OF THE CANCERS NATIONWIDE ARE RELATED TO CIGARETTE SMOKING, SOME PEOPLE WOULD HAVE US TAKE CIGARETTES OFF THE MARKET OR AT LEAST TO REGULATE THEIR ADVERTISING.

I HAVE INTRODUCED A BILL IN THE CONGRESS TO ROTATE THE WARNING LABELS ON CIGARETTE ADS AND PACKAGES, REMINDING SMOKERS OF THE DANGERS OF CANCER AND EMPHYSEMA, AND THE RISKS TO PREGNANT WOMEN. THE PRESENT SURGEON GENERAL ONCE SUPPORTED THIS BILL AND RECOGNIZED THE PREVENTIVE VALUE OF SUCH GRADUAL PATIENT EDUCATION.

BUT NOW THE ADMINISTRATION--INFLUENCED DIRECTLY BY THOSE FOR WHOM CONSUMER IGNORANCE IS PROFITABLE--REFUSES TO ENDORSE ANY PIECE OF LEGISLATION.

THIS PREDATORY SELF-INTEREST IS AS VIVID A POLITICAL "CON GAME" AS ANY I CAN IMAGINE IN WASHINGTON. IT IS PARTICULARLY TRAGIC IN THAT IT NOT ONLY CHEATS THE NATION OUT OF BILLIONS OF DOLLARS THAT MUST BE SPENT ON HEALTH CARE BUT ALSO OUT OF ITS VERY BREATH.

IN MUCH THE SAME MANNER, THE ADMINISTRATION HAS OPPOSED EVEN EXPERIMENTS IN PATIENT INFORMATION AND EDUCATION. THE CENTERS FOR DISEASE CONTROL ONCE CONDUCTED SMALL PROGRAMS PROVIDE MATERIALS FOR RISK REDUCTION ACTIVITIES. THESE PROGRAMS WERE LARGELY DIRECTED TO CURB THE ADOLESCENT SMOKING AND ALCOHOL ABUSE.

THEY WERE REPEALED LAST YEAR AT THE ADMINISTRATION'S REQUEST. THE WHITE HOUSE HAS DECIDED THAT EVEN SCHOOL CHILDREN WHO HAVE NOT YET FORMED THEIR HEALTH HABITS SHOULD LEARN THE HARD WAY THAT HEALTH AND MONEY CAN BE WASTED.

THE PILOT PROGRAMS TO ADVISE CONSUMERS ABOUT THE RISKS OR BENEFITS OF THEIR DIET HAVE BEEN STOPPED BY THE DEPARTMENT OF AGRICULTURE. THESE PILOT PROGRAMS PROVIDED SOUND INFORMATION ON FOOD AND HEART DISEASE THAT ONCE WAS AVAILABLE ONLY TO THOSE WHO HAD THE MONEY AND TIME TO CONSULT A CARDIOLOGIST.

NOW, ONCE AGAIN, THIS INFORMATION CAN BE HAD ONLY BY THOSE PEOPLE WHO CAN CONSULT A CARDIOLOGIST.

BUT EVEN MORE CONTROVERSIAL, THE ADMINISTRATION HAS ABRUPTLY CANCELLED THE MAJOR EXPERIMENT IN PHARMACEUTICALS THAT HAS BEEN IN THE MAKING FOR SOME TIME, SCRAPPING THE RESEARCH WITHOUT RESULTS. PATIENT PACKAGE INSERTS WERE FIRST ANNOUNCED AS A PILOT PROGRAM IN 1980. THESE INSERTS WERE TO PROVIDE A SIMPLE METHOD OF PASSING ON THE WARNINGS AND DETAILS THAT PHYSICIANS AND PHARMACISTS SIMPLY DON'T

PROVIDE ABOUT PRESCRIPTION MEDICINE.

AT THE TIME THE PROJECT WAS BEGUN, THE FDA SAID THAT INAPPROPRIATE USE OF THE TEN DRUGS TO BE ACCOMPANIED BY DESCRIPTIONS COST BETWEEN \$400 AND \$800 MILLION ANNUALLY. USING THIS ESTIMATE THE FDA WENT ON TO SAY THAT IF PPI'S MIGHT REDUCE THAT MISUSE BY ONLY 10%, THE PROJECT WOULD SAVE AS MUCH AS \$80 MILLION.

BUT RATHER THAN TEST THIS SORT OF PATIENT EDUCATION, HHS HAS CHOSEN A SORT OF "TRICKLE-DOWN" THEORY OF EDUCATION, HOPING THAT SOMEONE WILL TELL PREGNANT WOMEN OF THE RISKS AND UNKNOWNNS ABOUT THEIR MEDICINE OR THAT MAYBE SOMEONE ELSE WILL REMEMBER TO ASK IF THE PATIENT IS TAKING ANY OTHER MEDICATION.

ADMITTEDLY THERE WERE LOGISTICAL PROBLEMS WITH AN IMMEDIATE IMPLEMENTATION OF PPI'S ON ALL DRUGS. BUT RATHER THAN RESEARCH THE BENEFITS AND COSTS, THE ADMINISTRATION PRONOUNCED THE PROGRAM "UNREASONABLE" AND HAS PROCEEDED WITH ONE MORE EPISODE OF LETTING THE BUYER BEWARE.

AS WITH MANY OTHER PROGRAMS OF PREVENTIVE MEDICINE, THE ADMINISTRATION HAS PLEDGED ALLEGIANCE TO THE GOAL BUT THEN PROCEEDED TO DISMANTLE OR REPEAL WHATEVER EFFORTS WERE BEING MADE.

MY OWN STATE--CALIFORNIA--HAS RECENTLY CHOSEN TO TAKE A MORE DIRECT APPROACH TO CONSUMER INFORMATION, RECOGNIZING THAT THE INFANT MORTALITY RATES IN THE POORER AREAS OF THE COUNTRY ARE AS HIGH AS

THOSE IN MANY THIRD WORLD NATIONS, THE STATE FOOD AND DRUG AUTHORITY HAS DECIDED THAT PREGNANT WOMEN AND NURSING MOTHERS SHOULD BE TOLD THAT MANY OVER-THE-COUNTER DRUGS HAVE NOT BEEN TESTED FOR THEIR EFFECTS ON DEVELOPING FETUSES AND CHILDREN. THE CALIFORNIA LABEL WILL CAUTION CONSUMERS AND WILL FEATURE A LOGO FOR NON-ENGLISH SPEAKERS.

IN RESPONSE, THE FDA HAS ALSO DECIDED TO REQUIRE THAT THESE DRUGS BE LABELED, BUT HAS DECIDED NOT TO CAUTION CONSUMERS, BUT MERELY TO ADVISE THEM TO SEEK PROFESSIONAL ADVICE. SINCE THE TARGET GROUP OF THIS WARNING IS THOSE WOMEN--PRIMARILY POOR--WHO USE OVER-THE-COUNTER MEDICATION OFTEN BECAUSE THEY CANNOT AFFORD PROFESSIONAL ADVICE, THIS APPROACH SEEMS IRONICALLY UNHELPFUL.

IN LABELING, INSERTS, GUIDES, AND EDUCATION, THIS ADMINISTRATION HAS SHOWN ITSELF TO BE A FRIEND OF NEITHER EFFICIENT MARKETS NOR HELPLESS CONSUMERS.

THE ONLY PERSON WHO PROFITS FROM MISUSE OF A DRUG IS ITS MAKER. THE ONLY ONES WHO BENEFIT WHEN A TEENAGER LEARNS TO SMOKE ARE THE TOBACCO COMPANIES AND THE AD AGENCIES.

BUT WHILE SHORT-RUN PROFITS ARE MADE, TAXPAYERS AND INSURANCE COMPANIES PAY MEDICAL BILLS. PATIENTS STAY SICK LONGER.

THOSE OF YOU WHO REPRESENT THE MEDICAL PROFESSION WILL RECOGNIZE THE HEALTH COSTS. THOSE OF YOU WHO REPRESENT INDUSTRY WILL RECOGNIZE THE COSTS IN LOST PRODUCTIVITY AND INSURANCE PREMIUMS.

I HOPE THAT AS YOU REVIEW THIS CONFERENCE AND ARRIVE AT YOUR CONCLUSIONS, YOU WILL REMEMBER THESE COSTS AND THAT YOU WILL NOT CONCLUDE THAT THE REWARDS OF INFORMATION AND EDUCATION ARE INTANGIBLE. I'M SURE THAT NONE OF YOU WOULD BUY BONDS FROM A BROKERAGE THAT REFUSED TO GIVE YOU A PROSPECTUS. SURELY THE NATION'S HEALTH IS AS IMPORTANT AS THE NATION'S MARKETS.